NORD®
National Organization
for Rare Disorders

Peer to Peer FUNdraising Toolkit





Welcome to NORD®



WELCOME

Thank you for choosing to stand with the rare disease community. Your voice, your network, and your belief in what is possible have the power to move this mission forward in ways that truly matter. Together, we are building something bigger than any one of us… a future where no one navigating a rare disease is left without answers, support, or hope.

OUR MISSION

Improving the health and well-being of people with rare diseases by driving advances in care, research, and policy.

WHY PEER-TO-PEER FUNDRAISING MATTERS

Peer-to-peer fundraising brings this mission to life through people, connection, and shared purpose. When you invite others to give, you are not just raising funds… you are expanding awareness, building community, and opening doors to conversations that change lives. Your leadership inspires others to take action, creating a ripple effect that reaches far beyond a single gift.

IMPACT FOR THE COMMUNITY

Community fundraising fuels critical programs that support patients and families at every stage of their journey. From advancing research and education to providing access to trusted resources and advocacy, every dollar raised helps close the gaps that too many still face.

Because of you, more people find answers sooner, receive better care, and feel seen, supported, and connected.

Getting Started

WHAT IS PEER-TO-PEER FUNDRAISING?

Peer-to-peer (P2P) fundraising is when you raise money for a cause by asking people you already know to support it. Instead of one organization reaching out, many individuals share the mission with their own networks. It is simple, personal, and a powerful way to make a real impact.

RAISING MONEY ON BEHALF OF NORD

People choose to fundraise for NORD because the rare disease community is personal to them, whether they are living with a rare condition, supporting a loved one, or wanting to create connection and awareness.

They turn moments that matter, like hobbies, milestones, or shared experiences, into opportunities to give back. By sharing their story, they help others understand the impact and inspire support in a way only they can.





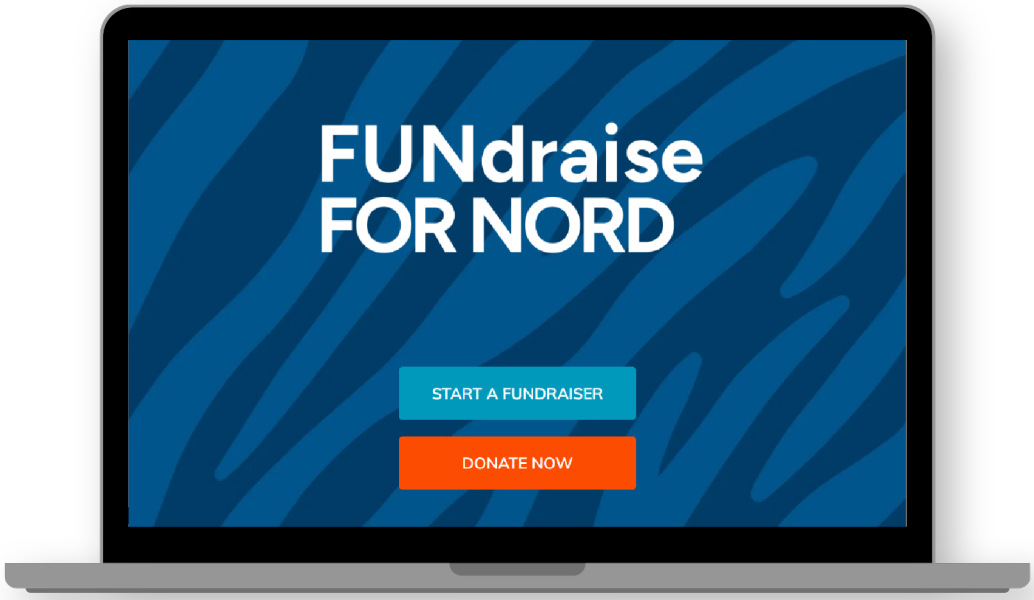
$120K+ Raised!

Stephanie Foster, alongside her parents Laurie and Steve, started a comedy night fundraiser grounded in her belief that laughter is the best medicine. Today, Steve and Laurie, together with their community, continue to honor Stephanie's legacy, raising more than $120,000!

Creating a FUNdraising page

STARTING A NORD FUNDRAISING PAGE

Creating your fundraising page is the first step in turning your passion into impact. In just a few minutes, you can set up a personalized page that tells your story and invites others to support the rare disease community. Every page helps expand awareness and drive meaningful change.



1

Start a Fundraiser

- Visit the NORD fundraising page and click “Start a Fundraiser.”
- Choose to create an individual or team fundraiser
- Set up your account with your name, email, and a password
- Customize your fundraising goal and page title

2

Tell Your Story

- Share why supporting the rare disease community matters to you
- Add photos or videos to make your page more personal
- Explain your connection to NORD or rare diseases
- Keep it authentic and heartfelt

3

Share Your Page

- Copy your fundraising page link and post it on social media
- Send it directly to friends and family via text or email
- Add updates to keep supporters engaged
- Don’t be afraid to remind people to give and share your page

Fundraising Idea Bank

START SMALL - FUNDRAISE IN 10 MINUTES OR LESS

- No-coffee or no-takeout week savings challenge
- Declutter and sell a few items locally (marketplace, tag sale)
- QR code donation shared in group chats
- "Match me if you can" post (small goal like $50–$100)
- Casual Dress Day in the office ($ for jeans)

YOU AND THE CREW

- Trivia or Game Night Entry Fee (virtual or in-person)
- Bake Sale
- Raffle
- Craft Sale
- Potluck dinner

FUNDRAISING WITHIN YOUR COMMUNITY

- Multi-day awareness + donation drive challenge (school or workplace)
- Fundraising Event
- Create-a-thon (dance, walk, read)



Social Media



Tag us in your posts!

- @NationalOrganizationforRareDisorders
- @nord_rare
- @RareDiseases
- @NationalOrganizationforRareDisorders
- @nord_rare

BEST PRACTICES

Lead with a human reason, not the link

Instead of "DONATE HERE" try "I'm fundraising for NORD because rare diseases affect 1 in 10 people in the U.S. This one is personal for me, and I'm trying to raise $500 this month." and add the link at the end!

Make sure you add the link correctly

Instagram: Link in bio
(Use Linktree or pinned "fundraiser" highlight)

Stories: Always use the donation link sticker if available or "link in bio" + swipe-style direction

Facebook: Direct link in post
(Best performing platform for donations)

LinkedIn: Link in post + comment with link repeated

TikTok: Link in bio + mention verbally in video

Show Your Progress!

People donate more when they see momentum

1. Use screenshots or a donation thermometer
2. Create milestone posts (First $100 Raised!)

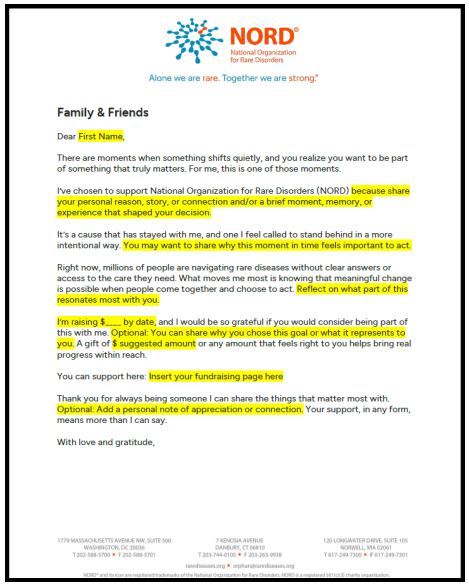
Make your page social media ready!

Does your fundraising page show:

1. A clear goal amount
2. A short personal story
3. A strong image

Pro Tip: Advice for Hashtags
We recommend you include 3-5 hashtags to help interested people find your posts. Try #RareDisease, #RareDiseases, #Fundraiser, and #Charity. Consider mentioning a specific disorder you have a connection to, use the hashtag for the name of that disorder.

Fundraising Letters



Alone we are rare. Together we are strong.®

Family & Friends

Dear First Name,

There are moments when something shifts quietly, and you realize you want to be part of something that truly matters. For me, this is one of those moments.

I've chosen to support National Organization for Rare Disorders (NORD) because share your personal reason, story, or connection and/or a brief moment, memory, or experience that shaped your decision.

It's a cause that has stayed with me, and one I feel called to stand behind in a more intentional way. You may want to share why this moment in time feels important to act.

Right now, millions of people are navigating rare diseases without clear answers or access to the care they need. What moves me most is knowing that meaningful change is possible when people come together and choose to act. Reflect on what part of this resonates most with you.

I'm raising $____ by date, and I would be so grateful if you would consider being part of this with me. Optional: You can share why you chose this goal or what it represents to you. A gift of $ suggested amount or any amount that feels right to you helps bring real progress within reach.

You can support here: Insert your fundraising page here

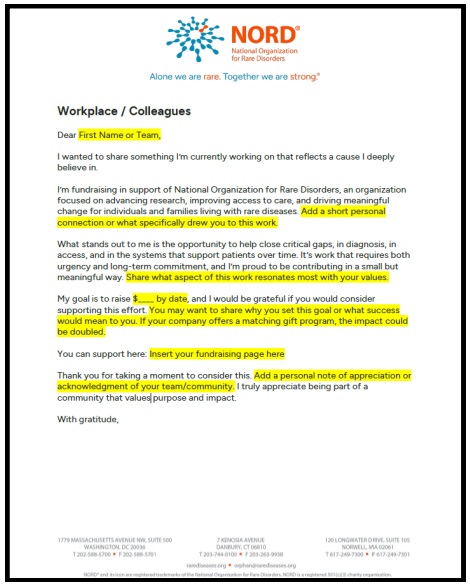
Thank you for always being someone I can share the things that matter most with. Optional: Add a personal note of appreciation or connection. Your support, in any form, means more than I can say.

With love and gratitude,

SAMPLE LETTER 1: FRIENDS AND FAMILY

[Click Here to Customize]

Reach out to the people who know you best. This letter helps you share your personal connection to rare disease and why this cause matters to you. Your story is the most powerful way to inspire support from those closest to you.



Alone we are rare. Together we are strong.®

Workplace / Colleagues

Dear First Name or Team,

I wanted to share something I'm currently working on that reflects a cause I deeply believe in.

I'm fundraising in support of National Organization for Rare Disorders, an organization focused on advancing research, improving access to care, and driving meaningful change for individuals and families living with rare diseases. Add a short personal connection or what specifically drew you to this work.

What stands out to me is the opportunity to help close critical gaps, in diagnosis, in access, and in the systems that support patients over time. It's work that requires both urgency and long-term commitment, and I'm proud to be contributing in a small but meaningful way. Share what aspect of this work resonates most with your values.

My goal is to raise $____ by date, and I would be grateful if you would consider supporting this effort. You may want to share why you set this goal or what success would mean to you. If your company offers a matching gift program, the impact could be doubled.

You can support here: Insert your fundraising page here

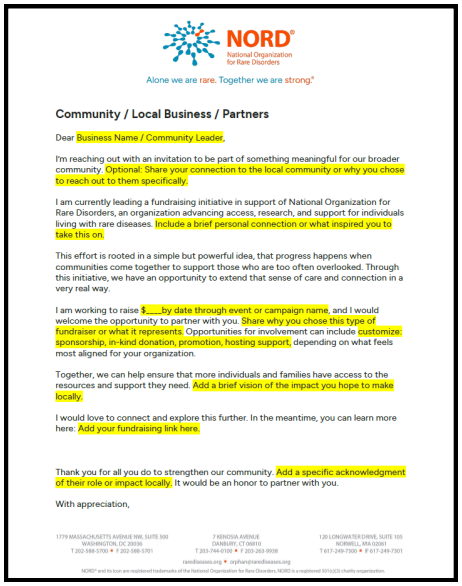
Thank you for taking a moment to consider this. Add a personal note of appreciation or acknowledgment of your team/community. I truly appreciate being part of a community that values purpose and impact.

With gratitude,

SAMPLE LETTER 2: WORKPLACE/COLLEAGUES

[Click Here to Customize]

Invite your professional network to be part of your impact. This version is designed to clearly communicate your goal, the mission behind your efforts, and how colleagues can support.



Alone we are rare. Together we are strong.®

Community / Local Business / Partners

Dear Business Name / Community Leader,

I'm reaching out with an invitation to be part of something meaningful for our broader community. Optional: Share your connection to the local community or why you chose to reach out to them specifically.

I am currently leading a fundraising initiative in support of National Organization for Rare Disorders, an organization advancing access, research, and support for individuals living with rare diseases. Include a brief personal connection or what inspired you to take this on.

This effort is rooted in a simple but powerful idea, that progress happens when communities come together to support those who are too often overlooked. Through this initiative, we have an opportunity to extend that sense of care and connection in a very real way.

I am working to raise $____by date through event or campaign name, and I would welcome the opportunity to partner with you. Share why you chose this type of fundraiser or what it represents. Opportunities for involvement can include customize: sponsorship, in-kind donation, promotion, hosting support, depending on what feels most aligned for your organization.

Together, we can help ensure that more individuals and families have access to the resources and support they need. Add a brief vision of the impact you hope to make locally.

I would love to connect and explore this further. In the meantime, you can learn more here: Add your fundraising link here.

Thank you for all you do to strengthen our community. Add a specific acknowledgment of their role or impact locally. It would be an honor to partner with you.

With appreciation,

SAMPLE LETTER 3: COMMUNITY

[Click Here to Customize]

Engage your broader community—local businesses, partners, and neighbors. This letter focuses on bringing your community together to support a shared cause and drive collective impact.

Assets to Support You

The following post copy and graphic can be customized to your personal story.



'I AM FUNDRAISING FOR NORD' INTRO POST

Click Here to Customize Your Graphic

Template post copy:

OPTION 1

I'm fundraising for the National Organization for Rare Disorders (NORD) to support people living with rare diseases. Right now, 1 in 10 Americans is affected by a rare disease, and many face long diagnostic journeys, limited treatment options, and high costs of care. My name is [Name], and I'm taking action by raising $[XXXX] to help make a difference. If you're able, please consider supporting or sharing my fundraiser: [link]

OPTION 2

I'm proud to be fundraising for the National Organization for Rare Disorders (NORD) to support a community that is often overlooked. People living with rare diseases face unique challenges, and organizations like NORD help provide resources, advocacy, and support when it's needed most. I'm raising $[XXXX] to contribute to this mission. You can help by sharing this post and donating here: [link]

OPTION 3

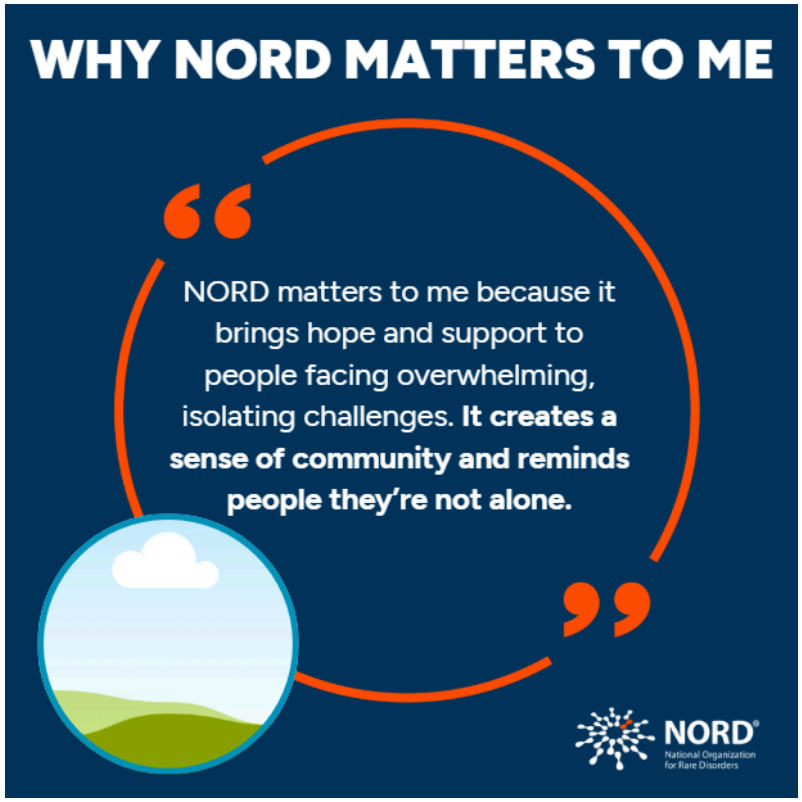
On [event/date], I'm fundraising for the National Organization for Rare Disorders (NORD) to help raise awareness and support for rare diseases. This cause matters to me because [personal reason], and I want to be part of creating meaningful change. My goal is $[XXXX], and every contribution helps. Support my fundraiser here: [link]

OPTION 4

Rare diseases impact millions of individuals and families, yet many still go without the support they need. That's why I'm fundraising for the National Organization for Rare Disorders (NORD). I'm [Name], and my goal is to raise $[XXXX] to support rare disease advocacy, education, and patient assistance. Join me by donating or sharing: [link]

Assets to Support You

The following post copy and graphic can be customized to your personal story.



'WHY NORD MATTERS TO ME' SHORT STORY POST

Click Here to Customize Your Graphic

Template post copy:

OPTION 1

The National Organization for Rare Disorders (NORD) matters to me because [personal reason or connection]. [Second sentence tying it to why you chose to fundraise]. If you'd like to support this cause, you can learn more or donate here: [link]

OPTION 2

I'm supporting the National Organization for Rare Disorders (NORD) because [reason]. For many people living with rare diseases, access to care, information, and support is not guaranteed. That's why this work is so important to me and why I chose to get involved. Support my fundraiser here: [link]

OPTION 3

This cause is personal to me. [1–2 sentences describing a story, observation, or belief.] The National Organization for Rare Disorders (NORD) is helping create change by supporting rare disease patients, families, and research efforts. If you're able, please consider supporting them here: [link]

Assets to Support You

The following post copy and graphic can be customized to your personal story.



"THANK YOU FOR YOUR SUPPORT" POST

Click Here to Customize Your Graphic

Template post copy:

OPTION 1

Thank you for your support. Because of you, I raised $[XXXX] for the National Organization for Rare Disorders (NORD). These funds will help support people living with rare diseases through patient assistance, advocacy, and access to critical resources. I'm grateful to everyone who donated or shared.

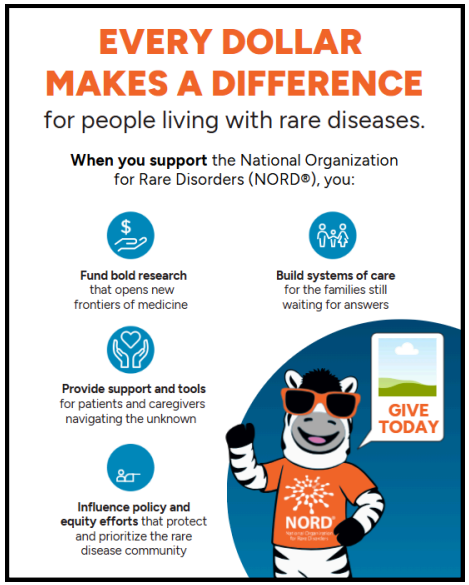
OPTION 2

We did it! Together, we raised $[XXXX] for the National Organization for Rare Disorders (NORD). Thank you to everyone who contributed to this effort. Your support helps fund programs that connect patients and families facing rare diseases to care, information, and support they might not otherwise have access to.

OPTION 3

Because of you, we raised $[XXXX] for the National Organization for Rare Disorders (NORD). This will help more people living with rare diseases access critical resources, navigate complex care systems, and find supportive community.

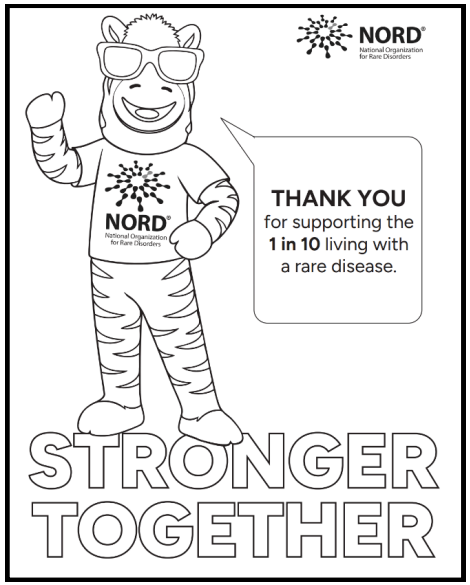
More Tools for Your Toolbox



EVENT TABLE SIGN

[Click Here to Customize]

Draw people in and spark conversation with a bold, mission-driven sign. Use it at your event to show how donations make an impact and inspire guests to give on the spot.



COLORING PAGE

[Click Here to Download]

Engage younger supporters with a fun, meaningful activity. This printable coloring page helps spread awareness while keeping kids connected to your cause.



STICKERS

[Click Here to Download]

Share your message far and wide. These stickers are perfect for giveaways, thank-yous, or adding a personal touch to your fundraising efforts.

NORD Branding



When you fundraise on behalf of the National Organization for Rare Disorders (NORD), you're representing a trusted, national voice for the rare disease community. Following NORD's brand guidelines helps ensure that everything you share is clear, consistent, and impactful.

WHY BRAND CONSISTENCY MATTERS

A consistent look and feel helps people instantly recognize NORD and builds trust with your audience. Whether you're posting on social media, creating flyers, or emailing supporters, using NORD's brand correctly strengthens your message and your fundraising efforts.

ACCESS THE ASSETS YOU NEED

Brand Guidelines
Before creating any materials, take a moment to review NORD's brand guidelines. This resource outlines everything you need to know about proper logo usage, colors, fonts, and messaging. Following these standards helps protect the integrity of NORD's brand and ensures your outreach feels cohesive.

Use the official logo
Always use NORD's approved logo files. Do not stretch, recolor, or alter the logo in any way. Make sure it's clear, readable, and has enough space around it.

Click here to download our logo.

NORD®
National Organization for Rare Disorders

Community Success

Community-driven fundraising has become a powerful force in advancing resources and hope for rare diseases. When patients, families, advocates, and local organizations unite around a shared cause, they not only generate critical financial support but also raise awareness, build networks, and accelerate scientific progress.

Individuals and families of those living rare, inspire community efforts such as the Benassi Family Oktoberfest, Ed for EDS4 Golf and Corn Hole Tournaments, Comedy Night honoring Stephanie Foster, the Odd Bellas Drag Show, exemplify how personal stories can mobilize broader support. By sharing lived experiences, hosting creative fundraising events, and leveraging business and social networks, these groups turn awareness into action and give voice to conditions that are often overlooked.

These grassroots efforts frequently lead to meaningful impact through NORD's mission They foster a sense of solidarity and hope, transforming isolated experiences into collective momentum. In the rare disease space, community success is not just measured in dollars raised, but in lives connected, voices amplified, and possibilities expanded.



$51K+ Raised!

Oktoberfest held at a brewery with entry tickets and raffles. "The Benassi family, alongside our business partners and friends, have broadened this idea to create an event to have some fun while helping others facing similar struggles."



$3.2K Raised!

The Odd Bella's created a fun and exciting Show!

After Your Fundraiser



CLOSING THE LOOP

Taking a moment to close the loop is a powerful act of stewardship. It honors the generosity of your supporters and shows them the real impact of what they made possible. When people feel the difference they've helped create, they are far more likely to stay connected to the mission.

SHARE HOW YOU DID

Thank Your Donors

Gratitude is the heart of every meaningful fundraising experience. A personal thank you reminds each donor that their gift mattered and was received with intention and care. It transforms a transaction into a relationship.

Share Results

Let your community know what you achieved together. Whether it is dollars raised, people reached, or stories shared, your results reflect the power of collective action. When you share the outcome, you help others see what is possible.

Post Highlights

Celebrate the moments that made your fundraiser meaningful. Photos, reflections, and stories bring your experience to life and inspire others to get involved. Your voice has the ability to spark the next wave of support.

STAY INVOLVED WITH NORD!

Your journey with this mission does not end here. There are so many ways to continue making an impact, from future fundraisers to advocacy and community engagement. We are grateful to stand alongside you, now and in the moments ahead!

Ready to get started?



THANK YOU

Because of your leadership, more people living with rare diseases are one step closer to answers, care, and connection. This is how momentum builds, and how lasting change begins. *We're here for you every step of the way!*

CONTACT

If you need any help along the journey, we're just an email away. Don't hesitate to reach out to us at: fundraise@rarediseases.org



Alicia Johnston
Development Associate



Jaime Pacheco
Senior Development Manager



Jenna Scheer, CFRE
Director of Philanthrophy

Alone we are rare. Together we are strong.®

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